

Providing Independent Living Support: Training for Senior Corps Volunteers

Module 5

Understanding Dementia

*Providing Independent
Living Support:
Understanding Dementia*



Trainer: _____

Date: _____

PROVIDING INDEPENDENT LIVING SUPPORT: TRAINING FOR SENIOR CORPS VOLUNTEERS

Module 5: Understanding Dementia

Introduction

This 60-75-minute session will explore what is normal for elders in the way of cognitive shortcomings and what are signs and symptoms that indicate a more serious problem. Participants will learn basic information about the different types and causes of dementia, including Alzheimer's disease, and how they can help clients and family members/caregivers cope. In addition to a lecture, this session includes a small group exercise and a closing reflection activity.

Objectives

By the end of the session participants will increase their understanding of:

- Causes, types, and warning signs of dementia
- What to expect from clients at different stages of dementia
- How to communicate with clients with dementia and what to consider in choosing activities

Visual Aids (PowerPoint) and Facilitator's Notes

If you are using the PowerPoint slides included with this curriculum, Facilitator's Notes are provided under each slide (to see them, select "View...Notes Page" from PowerPoint's main menu). These notes provide the same information as the Facilitator's Notes included in this document, however, they are not as detailed; the PowerPoint Facilitator's Notes are primarily main points for the presenter.

If you do *not* use the PowerPoint slides, we suggest you create other visual aids such as handouts or transparencies, or copy the information on easel paper and post it on walls or an easel for participants to see. The information on Slide 8 (exercise instructions) and Slides 9-12 on serving clients with dementia would be the most useful to duplicate and post.










Handouts

The handouts for this session follow the Facilitator's Notes and Instructions. Handouts 1-5 should be distributed during the session; this symbol in the Facilitator's Notes will cue you as to when: 📄. Handouts 6-7 can be distributed at the end of the session.

1. Alzheimer's Disease and Other Dementias
2. 10 Warning Signs of Alzheimer's Disease
3. Stages of Alzheimer's Disease
4. Tips for Assisting Clients with Dementia
5. Reflection: Preparing Yourself for Loss
6. Additional Resources: Understanding Dementia
7. Training Feedback Survey

Session Outline

Discussion Topic	Estimated Time	Method/Activity	Slide Numbers
I. Welcome and Introduction	10 min.		1
A. Learning Objectives	2	Lecture	2
B. Warm up: Cognitive Function and Aging	8	Lecture Large group callout	3-4
II. What is Dementia?	15 min.		
A. Types of Dementia  <i>Alzheimer's Disease and Other Dementias</i>	5	Lecture	5
B. Warning Signs and Stages of Alzheimer's Disease  <i>10 Warning Signs of Alzheimer's Disease</i>  <i>Stages of Alzheimer's Disease</i>	10	Lecture	6-7
III. Serving Clients with Dementia	45 min.		
A. Exercise: Match Game	15	Small groups (5 minutes) Debrief (15 minutes)	8
B. Working with the Client: Communication and Activities  <i>Tips for Assisting Clients with Dementia</i>	20	Lecture Large group callout	9-12
C. Reflection: Preparing for Loss  <i>Reflection: Preparing Yourself for Loss</i>	10	Individual, pairs	13
IV. Closing	5 min.		
Last Thoughts  <i>Additional Resources: Understanding Dementia</i>  <i>Training Feedback Survey</i>		Feedback	14

Facilitator's Notes and Instructions

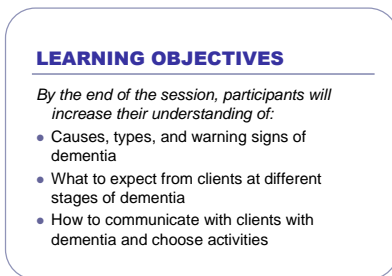


1

I. Welcome and Introduction

Show slide 1 – the title slide.

Explain the purpose of this training session: "To increase your understanding of what clients with dementia are experiencing and how you can assist them."



2

A. Learning Objectives

Show slide 2.

Read the learning objectives to the group. By the end of the session, participants will increase their understanding of:

- Causes, types, and warning signs of dementia
- What to expect from clients at different stages of dementia
- How to communicate with clients with dementia and what to consider in choosing activities



TIP: ADDRESS AS MANY CONCERNS AS YOU CAN. Dementia is a huge topic and you will not be able to address every concern in a short workshop. Consider putting packets of "Post it's" out on tables and asking participants to write down concerns or questions they may have as the workshop progresses. Post the notes on an easel and review them later, while participants are involved in the exercise. Try to address these concerns or questions during the session, or afterward, by referring participants to outside resources. There is a wealth of free, quality, easy-to-understand information available to the public through organizations such as The Alzheimer's Association.

DEMENTIA, COGNITIVE FUNCTION AND AGING

True or False?

1. *Forgetfulness is always a sign that something is wrong with your brain.*
2. *Everybody has different capacities for memory and these can change over a lifetime.*
3. *You lose 10,000 brain cells every day and eventually, you just run out.*
4. *Dementia is a normal part of aging.*

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B. WARM UP: Cognitive Function and Aging

Show slide 3.

Acknowledge that the topic of dementia is a little frightening for everyone: the disease is common and we all have concerns about maintaining a healthy mind and body as we age: “Let’s talk about some common beliefs around cognitive decline and aging. When we talk about ‘cognitive decline’ or ‘cognitive functioning’, we mean a person’s perception or awareness, the ability to think, reason, and learn.”

Large group callout: “Forgetfulness is always a sign that something is wrong with your brain.’ Is that true or false?”

Give participants a chance to respond, and then tell them this is false; it is a myth. If we didn’t possess the capacity to forget, we would all go crazy. The ability to remember what is important and discard the rest is a necessary skill. It is the level of forgetfulness that might indicate something is wrong. (Note you will be talking about warning signs in a few minutes.)

Large group callout: “Everybody has different capacities for memory and these capacities can change over the course of a lifetime. Is that true or false?”

This is true. Thus, comparing yourselves to others to see if your memory is normal is not a good measure.

Large group callout: “True or false: You lose 10,000 brain cells every day and eventually, you just run out.”

This is false – a myth. The reality is that some parts of the brain do lose nerve cells, but it’s possible to grow new ones and/or maintain the nerve connections of existing cells by exercising your mind.

Large group callout: “True or false: Dementia is a normal part of aging.”

This is false, another myth. Dementia is not a normal part of aging. It is true that most people who get dementia are over 65 (although people in their 40’s and 50’s can get it, too), but this percentage is fairly low until age 85 and older. For example, about 5 percent of people ages 65-74 have Alzheimer’s Disease, the most common cause of dementia, but about half of those age 85 and older are estimated to have it.

WHAT IS “NORMAL”?

Everybody is different, but in general...

- Creativity continues and wisdom accumulates.
- Information processing is slower (but repetition helps).
- “Multi-tasking” is more difficult.
- Long term memory declines somewhat (but cues help).
- Much of our language abilities stay the same or improve.

Source: American Psychological Association

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Show slide 4.

So what changes in mental ability is a normal part of aging (e.g. information processing, memory, the ability to “multi-task”, use of language, accumulation of new knowledge)?

Some of these abilities tend to decline as we age, while others will change only a little, and some will improve. For example, creativity can continue into our 90’s, and we can accumulate wisdom until the very end of life. Of course, changes in abilities vary by individual, but in general, as we age:

- We don’t process information as quickly, which sometimes means we need to have new information repeated to understand it.
- We are not able to divide our attention among a number of tasks as easily as when we are younger (sometimes referred to as “multi-tasking”).
- We experience some decline in long term memory as we age, although cues seem to help. Short-term memory is less affected as we age.
- We maintain or improve much of our language ability, such as vocabulary and comprehension, as we age.

Sources: Better Health Channel (2008), American Psychological Association (2008), National Institute on Aging (2008), National Senior Corps Association.



TIP: DISPEL MORE MYTHS. What other misconceptions might participants have about cognitive functioning and aging? If time allows, you may want to address them. However, be careful when conducting a myth-or-reality/true-or-false discussion. You want participants to retain the “reality” and not the myth (both of which they will hear); therefore, be sure to emphasize the reality in the lecture.

DEMENTIA INVOLVES DECLINE IN CORE MENTAL FUNCTIONS

1. Recent Memory
2. Language
3. Visuospatial Function
4. Executive Function



5

II. What is Dementia?

Show slide 5.

Dementia is the term used to describe types of brain disorders. There are many types of dementia; all types involve a mental decline that affects more than one of the four core mental functions:

1. Recent memory – the ability to learn and recall new information
2. Language – the ability to write or speak, or to understand written or spoken words
3. Visuospatial function - the ability to see and understand spatial relationships among objects (e.g. skills needed to use a map or do a jigsaw puzzle).
4. Executive function – the ability to plan, reason, solve problems and focus on a task.


Tell participants that you would like to look at the types of dementia, and then discuss the warning signs and stages.

A. Types of Dementia

There are many types of dementia. Some diseases and disorders that lead to dementia can be treated and reversed, but others get progressively worse. The most common type of irreversible (incurable) dementia is Alzheimer's disease.

Reversible (curable) dementia can be caused by high fever, dehydration, vitamin deficiency and poor nutrition, bad reactions to medicines, problems with the thyroid gland, or a minor head injury. Sometimes emotional problems can be mistaken for dementia; struggling with grief or anxiety, for example, leaves some people feeling confused or forgetful.

It is important to see a doctor to confirm a diagnosis of dementia. A diagnosis of dementia will rule out other conditions and allow the person and their family to make plans for their care.

 Distribute the handout *Alzheimer's Disease and Other Dementias*, which describes different types of dementias.



TIP: PRIORITIZE LECTURE TOPICS. Because there is so much information to cover in a short time, and you want to give participants a chance to share their own experiences, you may want to omit sections of the lecture (e.g. stages or types of dementia) and distribute a handout instead. See the *Facilitator's Guide* for more information on timing and training techniques.

**DEMENTIA INVOLVES DECLINE
IN CORE MENTAL FUNCTIONS**

1. Recent Memory
2. Language
3. Visuospatial Function
4. Executive Function



5

Briefly go through the most common types of dementia (below are seven, but you may want to just read the first few and refer participants to the handout for the rest):

- **Alzheimer's disease** – this is the most common form of dementia and accounts for between 50 and 70 per cent of all cases. It is a progressive, deteriorating illness that attacks the brain.
- **Vascular dementia** – this is the second most common type and is associated with problems of circulation of blood to parts of the brain.
- **Dementia with Lewy bodies (DLB)** – abnormal deposits of protein called Lewy bodies develop inside the brain's nerve cells.
- **Parkinson's disease** – this is a progressive disorder that attacks the part of the brain that controls movement. Many people with Parkinson's disease develop dementia in the later stages.
- **Huntington's disease** – this is an inherited, deteriorating brain disease that affects the mind and body.
- **Alcohol related dementia** (Wernicke-Korsadoff syndrome) - this is caused by too much alcohol and a poor diet low in Vitamin B1 (thiamine).
- **AIDS related dementia** – is caused by the HIV virus, but does not affect everyone with HIV-AIDS.

Diagnosing someone's type of dementia is not an easy process because symptoms and behaviors may appear before the brain clearly shows the cause. Doctors look at behaviors to determine which part of the brain is most affected, but not all dementia patients demonstrate the same types of behaviors. As with other diseases, doctors often treat symptoms and behaviors until a cause can be located and addressed.

Sources: Alzheimer's Disease Education and Referral Center (2008), Alzheimer's Association (2008), Better Health Channel (2008), National Senior Corps Association.



TIP: ENCOURAGE FURTHER LEARNING. Consider doing a "Part II" to this session by bringing in an expert on dementia to speak to volunteers and answer their questions. If *you* are an expert, consider allowing participants to stay after the session and ask you questions. Also encourage them to take the handout with "additional resources" and read more about this topic on their own.

WARNING SIGNS OF ALZHEIMER'S DISEASE



- Memory loss
- Difficulty in performing familiar tasks
- Language problems
- Disorientation to time and place
- Poor or decreased judgment
- Problems with abstract thinking
- Misplacing things
- Changes in mood or behavior
- Changes in personality
- Loss of initiative

Source: Alzheimer's Association

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B. Warning Signs and Stages of Alzheimer's Disease

Show slide 6.

  Distribute the two handouts: *10 Warning Signs of Alzheimer's Disease* and *Stages of Alzheimer's Disease*.

Tell participants you want to focus on Alzheimer's Disease because it is the most common type of dementia, accounting for 50% - 70% of all dementia cases: "Earlier we had mentioned that there is a difference between memory loss as a normal part of aging and memory loss as a symptom of something serious..."

Warning Signs of Alzheimer's Disease

Memory loss in a person with a disease like Alzheimer's is persistent and progressive, not just occasional. That is, they forget more often, and are unable to remember later; they may forget all or part of an event, and words and names of people and things they know. Over time, they lose the ability to follow a story narrative, follow directions, and perform everyday daily living tasks. According to the Alzheimer's Association, the top 10 warnings signs of Alzheimer's disease are:

- **Memory loss** (e.g. forgetting if they have eaten or that they no longer drive)
- **Difficulty in performing familiar tasks** (losing track in the middle of a task and being unable to complete it, such as preparing a meal, balancing a checkbook, turning off a stove, or combing hair)
- **Language problems** (forgetting words or substituting made-up words)
- **Disorientation to time and place** (becoming lost in their own neighborhood, not knowing what day it is)
- **Poor or decreased judgment** (wearing improper clothing, letting strangers in the house)
- **Problems with abstract thinking** (using numbers, maps)
- **Misplacing things** (putting things in inappropriate places, such as placing a pan in the freezer)
- **Changes in mood or behavior** (mood swings, such as crying or anger without apparent reason)
- **Changes in personality** (acting very much out of the ordinary, e.g. suddenly suspicious)
- **Loss of initiative** (sleeping too long; uninterested in activities)

STAGES OF ALZHEIMER'S DISEASE

- Stage 1: No cognitive impairment
- Stage 2: Very mild cognitive decline
- Stage 3: Mild cognitive decline
- Stage 4: Moderate cognitive decline
- Stage 5: Moderately severe cognitive decline
- Stage 6: Severe cognitive decline
- Stage 7: Very severe cognitive decline

Source: Alzheimer's Association

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Stages of Alzheimer's Disease

Show slide 7.

People with a disease that causes incurable dementia show a progressive decline in functioning ability. The speed of decline varies by individual and depends on the type of disease.

Alzheimer's disease generally starts by nerve cell degeneration. The progression of symptoms begins with the damage of nerve cells involved in learning and memory. The cell damage then spreads to cells that control other aspects of thinking, judgment, and behavior. Eventually cells that control and coordinate movement are damaged. Doctors have identified 7 stages of cognitive decline, organized by no observable symptoms to the most severe symptoms. By cognitive decline, we mean a decreasing ability to think and reason. Doctors know a patient's symptoms based on what they can observe directly, what the patient tells them, and/or what a third person (e.g. family member) tells the doctor.

(Go through the stages below or simply refer participants to the handout and skip to "In Summary" on the next page.)

Stage 1: No cognitive impairment: the person reports no memory problems and none are evident during a medical interview.

Stage 2: Very mild decline: the person feels they are forgetting things they shouldn't forget, but this is not apparent to others in their life.

Stage 3: Mild cognitive decline: the person's symptoms are apparent to others, such as forgetting common words, decreased ability to plan or organize. At this stage, symptoms *might* be measurable during clinical testing.

Stage 4: Moderate cognitive decline: At this stage and beyond, clinical tests would be able to measure problems, such as deficiencies in memory, ability to perform complex tasks and arithmetic.

Stage 5: Moderately severe cognitive decline: the person's symptoms include major gaps in memory and cognitive functioning (e.g. unable to remember details like their address) but they usually retain important knowledge about themselves and don't need help eating or using the toilet.

STAGES OF ALZHEIMER'S DISEASE

- Stage 1: No cognitive impairment
- Stage 2: Very mild cognitive decline
- Stage 3: Mild cognitive decline
- Stage 4: Moderate cognitive decline
- Stage 5: Moderately severe cognitive decline
- Stage 6: Severe cognitive decline
- Stage 7: Very severe cognitive decline

Source: Alzheimer's Association

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Stage 6: Severe cognitive decline: the person may experience personality changes and worsening memory, may need help getting dressed and using the toilet, may wander and experience problems sleeping and other difficulties.

Stage 7: Very severe cognitive decline: during the final stage of the disease, the person loses ability to speak, walk or control movement, or respond to people around them.

IN SUMMARY:

- Incurable dementia is a progressive decline in a person's functioning.
- There are many causes of dementia – Alzheimer's disease is the most common one.
- While dementia is more common in older people, it is not a normal part of aging.

Sources: Alzheimer's Association (2008), Better Health Channel (2008), National Senior Corps Association.

III. Serving Clients with Dementia

Tell participants you feel the need to take a break and lighten the session a little by having them play a short game.

A. EXERCISE: Matching Game*

The following exercise will help participants empathize with clients suffering from dementia. *Do not explain the purpose of the exercise until afterward.*

YOU WILL NEED: For each group, put 10 small items in a bag. The items should be chosen so that they can be paired in multiple ways; for example, they could be paired by color, size, type of material, purpose, or another way. Each bag should contain the same 10 items. (Example: The 10 items could include: a straw, a plastic lime, one dice, a laminated playing card, a small fish eraser, a pencil, a jack, a rubber ball, a small plastic dog, a small plastic man.)



TIP: PREPARE MATERIALS IN ADVANCE. This exercise takes a little more advance planning. You will need to collect materials and put them into bags ahead of time. Remember to think about how many participants will be at the workshop; divide that number by 3-4 person teams; and put together one bag for each team. For example, if you have 30 participants, you will need 8-10 bags.

Show slide 8.

EXERCISE: MATCHING GAME

Step 1. Split into small groups (teams of 3-4).

Step 2. Lay the objects from the bag on the table.

Step 3. Pair the like objects.



INSTRUCTIONS

1. Ask the participants to get into teams of 3 or 4.
2. Give each team one bag of items and ask them to take five minutes to “pair the like objects.” If people want more of an explanation, do not elaborate. The instructions are to “pair the like objects.”
3. As teams attempt to do this, walk around the room and observe. Say things like, “You know the instructions, don’t you? To pair the like objects?” Or “Keep trying. You’ll figure it out.” Or “Not quite, but you’re getting there.” These statements are meant to cause doubt and frustration.
4. After 5 minutes, call time (if they haven’t already given up), and start the debriefing.

DEBRIEF

Large group callout: “What happened?” “What were you feeling?”

People usually assume that there is one correct answer and get tangled up in logic trying to solve it. Participants may tell you things like:

- “I was frustrated because the exercise didn’t make sense.”
- “I didn’t understand how we were supposed to get the answer.”
- “We didn’t feel like we were given enough information.”
- “I didn’t feel like the facilitator was willing to help me.”

Tell participants, “There is no one correct way to pair the objects. Every team completed the exercise correctly no matter how they paired the objects. As long as the pairings made sense to the team, the team did it correctly.”

Large group callout: “What did you learn from this experience that might help you when you visit a client with dementia?”

The group will probably make the connection between the frustration and confusion they felt with the way someone with dementia feels. If that does not come up, explain that the exercise was a way to show them how a person with dementia feels and thinks. Tell participants that:

- Many tasks, no matter how simple they might seem, can quickly become frustrating.
- A person with dementia would not use logic to pair the objects. Dementia is about emotion— not about logic.

It would be natural for the group to start to identify ways to assist clients, given their experience with the exercise. Here are some suggestions:

- Be willing to provide simple instructions and repeat them as necessary with a calm and patient manner.
- Assist the client with tasks that are causing frustration, or create an environment that make the tasks easier (e.g. breaking it down into small steps).

Participants may come up with many good lessons, but the main lesson is: “If your client with dementia is busy and calm and you can provide encouragement instead of frustration, than you can create an environment that supports your client.”

*Thanks to Kathy Nelson for the Matching Game Exercise and her excellent notes.

B. Working with the Client: Communication and Activities

Show slide 9.

SERVING CLIENTS WITH DEMENTIA

The person with dementia...

- Is always right (from his/her point of view).
- Loses the ability to learn and record information.
- Does not need a reality check.
- Cannot control their behaviors.

Tell the participants that, now that they have had a little hands-on experience imagining the client’s feelings, you would like to talk about additional ways to improve interaction with clients. But first, as context, there are a few things they should remember about a person with dementia:

- **The person with dementia is always right (from his/her point of view)**, so reasoning and rationalizing will not help you. The person will not respond. Instead, use simple sentences about what is going to happen, or redirect his/her thoughts if he/she is upset. Remember from the matching game that logic is not helpful.

SERVING CLIENTS WITH DEMENTIA

The person with dementia...

- Is always right (from his/her point of view).
- Loses the ability to learn and record information.
- Does not need a reality check.
- Cannot control their behaviors.

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- **The person with dementia loses the ability to learn, and record information and events.** Setting conditions or making agreements (e.g. “If you’re going to make tea, don’t forget to turn off the stove”) will not work because the person will forget them. Instead, try to anticipate the problem and address it if possible (e.g. suggest the caregiver buy a tea kettle with an automatic “off” switch).
- **The person with dementia does not need a reality check.** Do not try to point out that something is not real or remind the person of something painful that they have forgotten and will forget again (e.g. the death of a loved one). Instead, redirect their thoughts; talk about something else or ask the person to tell you about the loved one.
- **The person with dementia cannot control their behaviors.** Physical changes in the brain are driving the person’s behaviors. Their sense of social skills and appropriate behavior are impaired because of these physical changes. They are not willfully “acting out” or making things difficult.

Tell participants you have some tips and suggestions for working with clients with dementia, but first, you would like to know what their experience has taught them, either with clients or other people in their life with dementia.



TIP: INVITE A GUEST SPEAKER. Depending on the time you can allot, participants can gain knowledge and empathy from hearing first-hand about people’s experiences with dementia. Ask a caregiver of someone with dementia, or a person with early dementia, to talk to the group about their experiences, including activities and communication strategies that work and don’t work.



SERVING CLIENTS WITH DEMENTIA: COMMUNICATION

- Use eye contact and face the person.
- Treat the person like an adult.
- Speak in clear, simple language.
- Praise and encourage often.
- Be willing to repeat and rephrase.
- Be a good listener.
- Remember: emotions speak louder than words.
- Be your normal, warm, outgoing self!

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Large group callout: “What advice do you have for improving communication with someone with dementia? How would you advise someone who is new to this?” (Ask one of the participants to assist by writing suggestions on easel paper.)

After a few minutes, show slide 10 and go over the main points, reinforcing any previous responses from the group.

Communication

Use eye contact and face the person. Get his/her attention by addressing him/her by name and saying who you are and why you are there.

Treat the person like an adult. Even though you will need to simplify what and how you say things, and repeat often, be careful not to let your tone unintentionally slip into condescension or disrespect.

Speak in clear, simple language; use direct short sentences; call people and things by name. Avoid using pronouns – call things by name. When giving directions, give them clearly and one step at a time.

Praise and encourage often. The client will react to your positive manner.

Be willing to repeat and rephrase. If you don’t get a response to a question, simplify it. Sometimes it is best to ask questions that are direct and require a yes/no response rather than open-ended (e.g. “Would you like chicken for lunch?” rather than “What would you like for lunch?”)

Be a good listener. Show with your body language and short affirmations (“yes, I see”) that you are paying attention and interested. Be patient if this is not the first time you’ve heard this; to the client, this is the first time they are telling you. If you don’t understand something, ask the client to point and gesture.

Emotions speak louder than words. Persons with dementia may have a hard time using language, so pay attention to the feelings behind the words.

Be your normal, warm, outgoing self!



Activities

Large group callout: “For those of you with experience caring for people with dementia, what kinds of activities have you tried that worked?”

Note their suggestions on easel paper and mention these points if they did not come up:

- Take the client on outings, if possible. Be sure to involve him/her in planning, and keep him/her informed and safe at all times. *Never leave the client alone.* Sometimes persons with dementia wander off and get lost so you must be alert.
- There may be activities you can do together that will help the client get exercise or maintain functional skills. For example, going for a walk around the neighborhood or gardening is exercise. Asking the client to assist you with tasks (e.g. helping you prepare a meal or clean up) may help him/her maintain functional skills longer.

Show slide 11.

SERVING CLIENTS WITH DEMENTIA: ACTIVITIES

- Focus on enjoyment of the process, not accomplishing something.
- Keep current skills and abilities in mind.
- Watch for signs of agitation; be ready to move on.
- Minimize distractions.
- Break the activity down into small steps.
- Encourage self expression.

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Tell participants that as they choose activities to do with their clients, they should keep these suggestions in mind:

Focus on enjoyment of the process, not accomplishing something. When the person decides the activity is done, then it is done.

Keep current skills and abilities in mind. Remember, skills and abilities can change quickly; what the person was able to do last week may not be doable this time.

Watch for signs of agitation; be ready to move on to something else. Have another activity in mind; if the client is showing signs of fatigue, switch to something relaxing, like sitting quietly and listening to music.

Minimize distractions. People with dementia often have diminished senses (hearing, seeing, etc.), which adds to the difficulty of focusing on a task.

Break the activity down into small steps to make it easier for the person to manage.

Encourage self-expression. This can be something simple like clapping or singing along to music, or something more complex like painting or storytelling.

Unpredictable or Disturbing Behavior

Show slide 12.

MANAGING DISTURBING BEHAVIOR

1. Distract or redirect.
2. Avoid arguing.
3. Bring the person back to a safe place.
4. Model correct behavior.

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Let participants know that they should be aware that clients may exhibit disturbing or unpredictable behavior such as dramatic mood swings, wandering away, aggression, hallucinations, etc. If this occurs, volunteers should try to:


Distract or redirect. Distract the client by pointing him/her to other activities, or talk about things he/she enjoys; redirect your client's thoughts to stop the disturbing behavior or forget what originally upset him/her.

Avoid arguing. Remember, this is not a good strategy no matter how good an orator you are. Instead, stay calm and keep a pleasant tone.

Bring the person back to a safe place. If you are on an outing, try to return your client to his/her home without risk to yourself or your client.

Model correct behavior (as usual), which may help your client imitate you and calm down.

Reiterate that, as they work with their clients with dementia, they will need to be patient, calm, reassuring, and creative in their responses. They will need to be observant and alert at all times to ensure the client's safety.

Distribute  *Tips for Assisting Clients with Dementia*, which summarizes some of the points just covered, and includes a few more.

Sources: National Senior Corps Association (special thanks to Kathy Nelson), Alzheimer's Association (2008), National Institute on Aging (2008), Family Caregiver Alliance (2004).



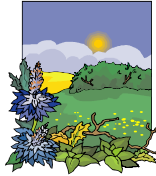
TIP: REVIEW PROGRAM POLICY. Now might be a good time to remind participants about your organization's policy and procedures for volunteer safety. What should a volunteer do in the event a client becomes suddenly aggressive, for example? Provide concrete examples and advice. Remind the volunteers where they can pick up a copy of your program's volunteer manual.

C. Reflection: Preparing for Loss

Show slide 13.

REFLECTION: PREPARING FOR LOSS

Sometimes, when
one person is
missing, the whole
world seems
depopulated.
~Lamartine



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Tell participants that grief naturally follows a loss-- loss of a loved one, loss of independence and responsibilities, loss of mental and physical capacities, etc.—and they will no doubt see clients dealing with grief. But volunteers may also deal with grief because they may lose the client as a friend as his/her memory disappears, the client is institutionalized, or passes away. It is important for volunteers to recognize that they may experience this loss of a client, and to prepare themselves psychologically.

Grief can manifest itself in many ways: physically, one might experience aches and pains, loss of sleep, or fatigue. Emotionally, there might be depression, guilt, anxiety, or frightening dreams, among others. If the grief is validated, than these manifestations will be seen as normal. Developing good coping skills such as being able to share painful thoughts with a friend, spiritual advisor, or support group, is one way to work through grief. Many people also find certain rituals and ceremonies to be of comfort and to help with the healing process. These might include keeping journal, planting a tree in honor of the person, lighting candles, attending religious services, gathering friends together to remember, or visiting a special place to quietly remember.

 Distribute the handout *Reflection: Preparing Yourself for Loss*.

Ask participants to take a few minutes to reflect on ways they cope with grief and how they would advise a friend. If they like, they should jot down notes and share their thoughts with a partner. Otherwise, this activity can be done individually or taken home to think about.

Source: National Senior Corps Association, Caregiver Legacy Services (2006).



TIPS: REMIND THEM OF PROGRAM SUPPORT. What does your program do to support volunteers when they lose a client? Do you give them a partial paid day off? Are there bereavement groups in your community that you recommend to volunteers? This is a good time to remind them they are not alone.

ENCOURAGE SHARING. Encourage participants to share feelings and ideas around this difficult topic of losing a client. Ask participants if they have experienced the loss of a client (including losing a client's friendship to the later stages of dementia); how did they cope and would they share with the group? If people are interested, consider doing a separate session on this topic.

LAST THOUGHTS...

"A friend is someone who knows the song in your heart and can sing it back to you when you have forgotten the words." ~unknown



You are appreciated!



14

IV. Closing

Show slide 14.

  Distribute other handouts: *Additional Resources: Understanding Dementia* and the *Training Feedback Survey*.

Tell participants that you would very much appreciate hearing their thoughts via the *Training Feedback Survey*. Let them know their responses are anonymous (no names are required on the surveys), and that the surveys are collected to help improve future training sessions. Make sure to indicate where you would like the completed surveys to be placed.

Leave the group with this quote (unknown source): "A friend is someone who knows the song in your heart and can sing it back to you when you have forgotten the words." There is a Native American tradition where infants are given a song at birth. As they grow, the community is responsible to help them remember who they are by singing the song in times of hardship.

Remind participants that they provide a difficult but extremely valuable service.

Thank everyone for coming.



TIP: END ON A POSITIVE NOTE. Dementia is a frightening and depressing topic; you will need to be creative to end the workshop on a positive note! Remind participants of how important they are in their client's lives. Do you have "thank you" letters from caregivers of former clients? With their permission, share some of the quotes about how much these caregivers appreciated what the volunteers did for their loved ones. Another option might be to read a passage, or listen to the audio, from an inspiring book (e.g. "Still Alice" by Lisa Genova is a fictional account recommended by the Alzheimer's Association).

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Handouts

The following handouts are included in this module:

1. Alzheimer's Disease and Other Dementias
2. 10 Warning Signs of Alzheimer's Disease
3. Stages of Alzheimer's Disease
4. Tips for Assisting Clients with Dementia
5. Reflection: Preparing Yourself for Loss
6. Additional Resources: Understanding Dementia
7. Training Feedback Survey

*Providing Independent
Living Support:*
Understanding Dementia



Trainer: _____

Date: _____

Alzheimer's Disease and Other Dementias

About dementia

Dementia is a general term for a group of brain disorders. Alzheimer's disease is the most common type of dementia, accounting for 50 to 70 percent of cases. This fact sheet briefly discusses Alzheimer's and some other dementias.

All types of dementia involve mental decline that:

- occurred from a higher level (for example, the person didn't always have a poor memory)
- is severe enough to interfere with usual activities and daily life
- affects more than one of the following four core mental abilities
- recent memory (the ability to learn and recall new information)
- language (the ability to write or speak, or to understand written or spoken words)
- visuospatial function (the ability to understand and use symbols, maps, etc., and the brain's ability to translate visual signals into a correct impression of where objects are in space)
- executive function (the ability to plan, reason, solve problems and focus on a task)

Alzheimer's disease

Although symptoms can vary widely, the first problem many people with Alzheimer's notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior.

These symptoms result from damage to the brain's nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles. For more detailed information about Alzheimer's disease, please visit our Web site www.alz.org or contact us at 1.800.272.3900.

Mild cognitive impairment (MCI)

In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. The best-studied type of MCI involves a memory problem.

Individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another kind of dementia.

Vascular dementia (VaD)

Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of

food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called “post-stroke dementia.”

It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be called “multi-infarct dementia.”

Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in “steps,” where there is a fairly sudden change in function.

People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

Mixed dementia

In mixed dementia, Alzheimer’s disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer’s and vascular disease.

Decline may follow a pattern similar to either Alzheimer’s or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.

Dementia with Lewy bodies (DLB)

In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain’s nerve cells. These deposits are called “Lewy bodies” after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson’s disease and some cases of Alzheimer’s.

Symptoms of DLB include:

- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer’s disease
- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls
- Excessive daytime drowsiness
- Visual hallucinations
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not “act out” their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

Parkinson's disease (PD)

Parkinson's is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson's develop dementia in later stages of the disease.

Frontotemporal dementia (FTD)

FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick's disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies.

FTD progresses more quickly than Alzheimer's disease and tends to occur at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or off-color remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells.

Recently, "variant Creutzfeldt-Jakob disease" (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by "mad cow disease." It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve impairment in memory, thinking and reasoning or changes in personality and behavior. Depression or agitation also tend to occur early. Problems with movement may be present from the beginning or appear shortly after the other symptoms. CJD progresses rapidly and is usually fatal within a year.

Normal pressure hydrocephalus (NPH)

Normal pressure hydrocephalus (high-droh-CEFF-a-luss) is another rare disorder in which fluid surrounding the brain and spinal cord is unable to drain normally. The fluid builds up, enlarging the ventricles (fluid-filled chambers) inside the brain. As the chambers expand, they can compress and damage nearby tissue. "Normal pressure" refers to the fact that the spinal fluid pressure often, although not always, falls within the normal range on a spinal tap.

The three chief symptoms of NPH are (1) difficulty walking, (2) loss of bladder control and (3) mental decline, usually involving an overall slowing in understanding and reacting to

information. A person's responses are delayed, but they tend to be accurate and appropriate to the situation when they finally come.

NPH can occasionally be treated by surgically inserting a long thin tube called a shunt to drain fluid from the brain to the abdomen. Certain television broadcasts and commercials have portrayed NPH as a highly treatable condition that is often misdiagnosed as Alzheimer's or Parkinson's disease. However, most experts believe it is unlikely that significant numbers of people diagnosed with Alzheimer's or Parkinson's actually have NPH that could be corrected with surgery. NPH is rare, and it looks different from Alzheimer's or Parkinson's to a physician with experience in assessing brain disorders. When shunting surgery is successful, it tends to help more with walking and bladder control than with mental decline.

Huntington's disease (HD)

HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington's has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington's disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:

- confusion, permanent gaps in memory and problems with learning new information
- individuals may have a tendency to "confabulate," or make up information they can't remember
- unsteadiness, weakness and lack of coordination

If the condition is caught early and drinking stops, treatment with high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated September 2006

10 warning signs of Alzheimer's disease®

Memory loss that disrupts everyday life is not a normal part of aging. It is a symptom of dementia, a gradual and progressive decline in memory, thinking and reasoning skills. The most common cause of dementia is Alzheimer's disease, a disorder that results in the loss of brain cells.

The Alzheimer's Association, the world leader in Alzheimer research and support, has developed a checklist of common symptoms to help recognize the warning signs of Alzheimer's disease.

- 
- 1 Memory loss
 - 2 Difficulty performing familiar tasks
 - 3 Problems with language
 - 4 Disorientation to time and place
 - 5 Poor or decreased judgment
 - 6 Problems with abstract thinking
 - 7 Misplacing things
 - 8 Changes in mood or behavior
 - 9 Changes in personality
 - 10 Loss of initiative

[Learn more](#) ▷

the compassion to care, the leadership to conquer

10 warning signs What's considered normal and what's not

1 Memory loss

Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.

What's normal? Forgetting names or appointments occasionally

2 Difficulty performing familiar tasks

People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps to prepare a meal, place a telephone call or play a game.

What's normal? Occasionally forgetting why you came into a room or what you planned to say

3 Problems with language

People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth."

What's normal? Sometimes having trouble finding the right word

4 Disorientation to time and place

People with Alzheimer's disease can become lost in their own neighborhoods, forget where they are and how they got there, and not know how to get back home.

What's normal? Forgetting the day of the week or where you were going

5 Poor or decreased judgment

Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment about money, like giving away large sums to telemarketers.

What's normal? Making a questionable or debatable decision from time to time

6 Problems with abstract thinking

Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are and how they should be used.

What's normal? Finding it challenging to balance a checkbook

7 Misplacing things

A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.

What's normal? Misplacing keys or a wallet temporarily

8 Changes in mood or behavior

Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

What's normal? Occasionally feeling sad or moody

9 Changes in personality

The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

What's normal? People's personalities do change somewhat with age

10 Loss of initiative

A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

What's normal? Sometimes feeling weary of work or social obligations

Get the best health care for memory loss by
"Partnering With Your Doctor."
Contact the Alzheimer's Association
for information about this educational workshop.



Why can't I remember her name? **Is memory loss a normal part of aging?**

Everyone forgets a name or misplaces keys occasionally. Many healthy people are less able to remember certain kinds of information as they get older.

The symptoms of Alzheimer's disease are much more severe than such simple memory lapses. Alzheimer symptoms progress, affecting communication, learning, thinking and reasoning. Eventually they have an impact on a person's work and social life.

What's the difference?

Someone with Alzheimer symptoms	Someone with normal age-related memory changes
Forgets entire experiences	Forgets part of an experience
Rarely remembers later	Often remembers later
Is gradually unable to follow written/spoken directions	Is usually able to follow written/spoken directions
Is gradually unable to use notes as reminders	Is usually able to use notes as reminders
Is gradually unable to care for self	Is usually able to care for self

If you or someone you know is experiencing these symptoms, consult a physician today. Early and accurate diagnosis of Alzheimer's disease or other dementias is an important step to getting the right treatment, care and support.

For reliable information and support,
contact the Alzheimer's Association:

1.800.272.3900

www.alz.org

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Stages of Alzheimer's Disease

Experts have documented common patterns of symptom progression that occur in many individuals with Alzheimer's disease and developed several methods of "staging" based on these patterns. Progression of symptoms corresponds in a general way to the underlying nerve cell degeneration that takes place in Alzheimer's disease.

Nerve cell damage typically begins with cells involved in learning and memory and gradually spreads to cells that control other aspects of thinking, judgment and behavior. The damage eventually affects cells that control and coordinate movement.

Staging systems provide useful frames of reference for understanding how the disease may unfold and for making future plans. But it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another. Not everyone will experience every symptom and symptoms may occur at different times in different individuals. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.

The framework for this fact sheet is a system that outlines key symptoms characterizing seven stages ranging from unimpaired function to very severe cognitive decline. This framework is based on a system developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Within this framework, we have noted which stages correspond to the widely used concepts of mild, moderate, moderately severe and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, mid-stage and late-stage categories.

Stage 1: No cognitive impairment

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2: Very mild decline

Individuals at this stage feel as if they have memory lapses, forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

Stage 3: Mild cognitive decline

Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people

- Performance issues in social and work settings noticeable to others
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

Stage 4: Moderate cognitive decline
(Mild or early-stage Alzheimer's disease)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent events
- Impaired ability to perform challenging mental arithmetic. For example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

Stage 5: Moderately severe cognitive decline
(Moderate or mid-stage Alzheimer's disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

Stage 6: Severe cognitive decline
(Moderately severe or mid-stage Alzheimer's disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet

- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

Stage 7: Very severe cognitive decline

(Severe or late-stage Alzheimer's disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated October 2003

Tips for Assisting Clients with Dementia

Following are suggestions for how you might assist your client with dementia while ensuring he/she is safe. We offer tips for communicating with your client, choosing activities (including taking your client on an outing), and managing disturbing or unpredictable behavior such as hallucinations and wandering.



Communicating with your Client

1. To get your client's attention without startling him/her, gently place a hand on the shoulder to indicate someone is there. Call your client by name, and remind him/her who you are and why you are there. If your client doesn't recognize you every time, remember not to take it personally.
2. Use eye contact and face the client.
3. Use simple words, but avoid talking down to your client; speak on a normal adult level, but speak clearly and not too fast. Use specific words and names rather than pronouns.
4. If you give directions, be clear and concise; explain one step at a time. Praise and encourage him/her with your words and body language.
5. Smile often, and listen patiently without trying to correct what your client says, even if it is not reality. Know when to let go of the desire to reason with him/her. If the client thinks one thing and you know differently, arguing about it is not going to change his/her mind. Agreeing with the client is often the best thing to do.
6. Be a good listener and pay attention to your client. Discuss familiar subjects with your client. Refrain from discussing controversial or depressing subjects, and please do not burden your clients with your own problems.
7. Ask one question at a time and wait patiently for a response. If you don't get one, wait a moment and ask again. Try rephrasing your question.
8. Try not to get frustrated when hearing the same thing over and over. To the client, this is the first time they have told you. If your client is unable to think of a word, gently give him/her a hint and say that you forget, too. If your client loses train of thought, repeat the last thing said to help get him/her back on track. If the client forgets your name, gently work it into the conversation and why you are there. Be patient when you have to repeat yourself.
9. Sometimes people with dementia substitute real words with invented or inappropriate words. If you don't understand what your client is trying to tell you, ask him/her to point and show you.
10. Focus on the emotions the client is expressing rather than the words he/she is saying. Validate his/her feelings with your own words and body language. This will help your client trust you and reduce his/her anxiety.
11. Be your normal understanding, warm, and outgoing self!

Remember to keep your client visits confidential; do not share outside of the program's environment!

Choosing an Activity

1. When choosing an activity, keep the person's current skills and abilities in mind (i.e. be aware of changing mental and physical limitations). Be ready to drop the activity and move on to something else if your client is not enjoying it. Watch for signs of agitation.
2. Help your client get started on an activity. Minimize distractions so he/she can focus. Break the activity down into small steps, praising your client for steps accomplished and gently helping with difficult parts.
3. Encourage self-expression; try activities that involve art, music, and storytelling. For example, put on familiar music and reminisce over photographs, or help your client work on a painting by setting up all the tools needed and talking about what they are painting.
4. Focus on enjoyment of the process, not achieving a result. Allow your client as much independence as is safely possible. When your client decides he/she has finished the activity, then it is done.
5. Help your client maintain functional skills and feel needed by having them assist with daily tasks. For instance, at mealtimes, encourage him/her to help prepare the food, set the table, and wash dishes.
6. Help your client get exercise (if health permits) by taking a walk outside or doing something else the person enjoys (e.g. gardening). Exercise during the day helps people sleep better at night.

Take your client on outings, if you can. Go to places that are familiar, and avoid places that are crowded and hectic.

- Involve your client in planning the outing. Decide together when you will go, where you will go, and how you will get there. For example, you can offer to assist with any tasks involving errands, shopping etc, but let your client choose where to shop. If he/she uses medical equipment, be sure you know how it works before you go out.
- Keep your client well-informed (*We're getting into the car to go to.....we're getting out of the car to go to...*). Don't rush. If necessary, help him/her to get ready for the outing. Assist your client side-by-side and door-to-door.
- Make sure your client is safe and help him/her feel comfortable the whole time. *Never leave the client alone*. Offer an arm if necessary to give him/her stability and security. Sit next to him/her and explain what is going on.

Managing disturbing behavior

Your client may exhibit disturbing behavior such as hallucinating, becoming suddenly emotional for no reason that is apparent, insisting something is true that isn't, or wandering away. Prepare yourself for this possibility. Keep in mind that difficult behavior might be the result of an unmet need; because verbal communication is difficult for people with dementia, the need may be expressed in other ways (e.g. aggression, agitation, anxiety, wandering, etc.).

Always remember it is the disease that is causing this behavior; your client is not acting that way on purpose. In general:

- Through communication with the client, bring him/her back to a safe place (mentally and physically) if possible. If you are on an outing, try to return your client to his/her home without risk to yourself or your client. Distract the client by pointing him/her to other activities, or talk about things he/she enjoys; redirect your client's thoughts to stop the disturbing behavior or forget what originally upset him/her.
- It may be necessary to speak firmly but gently to the client concerning the inappropriate behavior, as you model correct behavior. Don't be afraid to correct the client and explain why the behavior is not appropriate; however, do not argue or become upset, as your client may respond in the same way. Address the situation in a calm manner.

Hallucinations and delusions can be frightening for both you and your client, and are not uncommon during later stages of dementia. Hallucinations occur when the person sees, hears, smells, tastes, or feels something that is not there. Delusions occur when the person believes something that is not true and cannot be convinced otherwise. If this happens while you are with your client, the National Institute on Aging recommends:

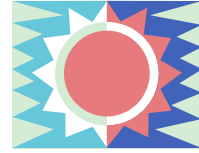
1. Avoid arguing about what he/she believes is happening. Instead, try to respond to the feelings he/she is expressing, and provide reassurance and comfort.
2. Try to distract your client to another topic or activity. Sometimes simply moving to another room is enough.
3. The client may not be able to distinguish what he/she is watching on television from reality. Try to be aware of the kinds of things that upset your client and do not watch shows/movies that might trigger these emotions.
4. Make sure you and your client are safe, and that your client does not have access to anything he/she could use to harm anyone.

Wandering is another frightening possibility; thus, you should never leave your client alone. The National Institute on Aging recommends that caregivers enroll the person in the Alzheimer's Association Safe Return program and notify neighbors and local authorities in advance if the person has a tendency to wander. You may wish to keep a recent photograph of your client in case he/she becomes lost.

LAST SAFETY NOTE: Be aware that dementia can impair your client's five senses: seeing, hearing, tasting, feeling, and smelling. This means your client may not be able to smell or taste spoiled food; gauge the temperature of water or food before touching/eating it; distinguish outside noises from inside, or voices on the radio from a person in the house; notice a small pet laying in the hallway or see the edges of steps; or protect him/herself from countless other potential hazards. Your careful observance, sensitivity, and quick thinking can make all the difference!

Sources: National Senior Corps Association (NSCA): www.nscatogether.org. Alzheimer's Association: www.alz.org; National Institute on Aging. www.nia.nih.gov

Reflection: Preparing Yourself for Loss



If you suppress grief too much, it can well redouble. ~Moliere

Take a few minutes to reflect on the friendship you share with your client (if applicable). Jot down some notes and if you care to, share your thoughts with a partner.

Some people who have lost someone find comfort in activities like planting a tree, lighting candles, attending spiritual ceremonies, or writing a letter to the person. Do you have a favorite ritual or ceremony to help you cope with a loss? If yes, what is it?

What advice would you give a friend who has recently lost someone special to help them cope?

Are you or someone you know having difficulty coping with a loss? Don't suffer alone. Ask your supervisor if he/she can refer you to bereavement counseling or support groups. Local hospitals, hospices, and area agencies on aging may also be able to refer you to helpful resources.

Additional Resources: Understanding Dementia

Are you interested in learning more about the topics covered in this workshop? You may find the following online resources helpful. References consulted for this module are also included in this handout.

The **Alzheimer's Association** is a leading voluntary health organization in Alzheimer care, support and research. This website contains a wealth of accessible information including explanations of what is known about Alzheimer's disease and the current research; resources available for caregivers; and an online platform that allows people in the early stages to share their experiences: <http://www.alz.org/index.asp>.

The **Eldercare Locator** is a national toll-free directory assistance service provided by the U.S. Administration on Aging. Eldercare Locator helps people locate aging services in every community throughout the U.S. Call 1-800-677-1116 or visit their website: <http://www.eldercare.gov>.

Family Caregiving 101 is sponsored by The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC). This website is designed to provide caregivers with the basic tools, skills and information they need to protect their own physical and mental health while they provide care for a loved one: www.familycaregiving101.org/.

The **Mayo Clinic** website provides health information on a range of topics, including Alzheimer's disease, dementia, and caregiving, as well as other senior health care and wellness issues: <http://www.mayoclinic.com/>.

TimeSlips Project, developed by the Center on Age and Community at the University of Wisconsin, Milwaukee, is a creative storytelling method for people with dementia and their caregivers. The method is based on "shifting the emphasis from memory or factual reminiscence to opening and validating the imagination." Training materials are available for purchase, but just browsing the website may inspire ideas for creative activities with your client. <http://www.timeslips.org/>.

Your Home – Caring for those with Alzheimer's Disease is a website developed by nationally recognized experts on Alzheimer's disease and caregiving. The website is available in English and Spanish, audio or written text, and provides basic information on symptoms, visits to the doctor, stages of the disease, dealing with behaviors, planning for the future, and caring for the caregivers: <http://www.positiveaging.org/alz/>.

In addition, the following three resources were recommended by the National Senior Corps Association:

- Book: "The Family on Beartown Road: A Memoir of Love and Courage" by Elizabeth Cohen. Publisher: Random House Trade Paperbacks (2004).
- Website: Naomi Feil's validation theory website <http://www.vfvalidation.org/> for information on communicating with people with dementia.
- Video: "Complaints of a Dutiful Daughter" (1994) and others available through the Alzheimer's Association: <http://www.alz.org/index.asp>.

Module References

Alzheimer's Association: <http://www.alz.org/index.asp>.

2007. Alzheimer's Disease and Other Dementias.

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2005. 10 Warning Signs of Alzheimer's Disease.

American Psychological Association. What are the Cognitive Changes Associated with Normal Aging? <http://www.apa.org/pi/aging/practitioners/realities08.html> (accessed June 2, 2008).

Better Health Channel. Dementia and Memory Loss.

http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Dementia_and_memory_loss?OpenDocument (accessed June 2, 2008).

Family Caregiver Alliance. 2004. 10 Real-Life Strategies for Dementia Caregiving. SLC Aging Service Subscription, Vol. 21, No. 3. http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1134.

Legacy Caregiver Services. 2006. *The caregiver helpbook: powerful tools for caregivers*. Legacy Health System: Portland, Oregon.

National Senior Corps Association. <http://www.nscatogether.org/>.

U.S. National Institutes of Health, National Institute on Aging, Alzheimer's Disease Education and Referral Center (ADEAR). www.nia.nih.gov/Alzheimers/.

Training Feedback Survey

Please help us improve our training sessions by providing feedback on the training you attended. Thank you!

Training/Session Name: _____ Date: _____

Lead Facilitator: _____

Program you serve with: ☐ SCP ☐ RSVP ☐ Other: _____

Please rate this session using the following scale:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	1	2	3	4	5
1. The subject matter was presented effectively.					
2. The facilitator was knowledgeable.					
3. The facilitator responded to questions.					
4. There were enough opportunities for discussion.					
5. The written materials are useful.					
6. The session met my expectations.					
7. As a result of this training, I gained new knowledge applicable to my volunteer assignment.					
8. I plan to apply what I learned at this session.					

9. What did you like best about this session?

10. What would have improved this session?

Thank You! Your feedback will help us to improve our training!